A GUIDE TO ARRIVING AT A RATING FOR OUTCOME 1.3
MY RIGHTS ARE PROTECTED

A "DECISION TREE" FOR SURVEYORS

INTRODUCTION

Outcome 1.3 (People's rights are protected) evaluates whether interventions are the least intrusive and based on individual needs. It is each person's right to be supported solely through positive means whenever possible, with restrictive interventions being implemented only when less intrusive interventions have been unsuccessful and only when required safeguards have been observed. Outcome 1.3 is rated for all individuals including those at the least intrusive end of the continuum, with no negative interventions, to those at the other end of the continuum, with very restrictive interventions.

When determining whether people's rights are protected, it is important to look beyond any formalized individual interventions and review whether there are any practices, directly or indirectly, in the person's surroundings or programming that pose a restriction. Are there restrictive house rules, for example, that interfere with the person's rights? Are there automatic restrictions for certain behaviors? Are their bed checks during the night for all individuals?

When using such interventions such as behavior plans, physical restraint, and behavior modifying medication that can and do have the potential to impact on a person's dignity, health and safety, it is incumbent upon the provider to evaluate issues of risk, intrusiveness or restrictiveness. It is important to assure the interventions are clinically sound, incorporate strategies to reduce the need for the intervention over time, to have the highest level of review and be implemented consistently and safely. While surveyors do not make clinical judgments regarding the interventions themselves, they are expected to evaluate how the provider assures:

- that all interventions are the least intrusive and are based upon people's unique needs;
- that all interventions are included in a written plan;
- that people, or their guardians, knowingly and voluntarily give consent and have the opportunity to refuse or withdraw approval;
- that safeguards ensure a thorough review and approval process when needed; and
- that all interventions are safely, accurately and consistently implemented.

What to Consider in Rating 1.3

1.3A is answered for all individuals. Questions to assist in answering the indicator include:

- Is the individual supported only through positive means?
- Are all interventions based on the individual's unique needs?
- Are all interventions consistent with the individual's learning style?

- Have any restrictive interventions been faded over time?
- Are there any restrictive practices without needed safeguards, such as house rules, that restrict the individual's rights?

Indicators B, C, D and E would be answered only when restrictive interventions are in place for the individual. These would include:

BEHAVIOR PLANS

- Level II and III interventions
- Level I interventions with a negative component. They would also be answered if the plan contained interventions that were intended to be positive, but were viewed negatively by the person and were generally upsetting to him or her. Example: A plan has been implemented where an individual is praised each time she sets the table appropriately. She initially becomes upset by the praise until staff explains to her that they are giving her a compliment.

MEDICATIONS TO CONTROL OR MODIFY BEHAVIOR

The specific requirements of 115 CMR 5.15(4) with respect to behavior modifying medications only applies where the program administers the medication to the individual. Therefore, indicators B,C,D and E are always answered where the person is taking medication to control or modify behavior and the provider is administering the medication. The rationale is that where an individual needs support to take his or her medications then he or she also needs support in other aspects in the use of the medication. A plan would be required for individuals who are under guardianship as well as those individuals who do not have a guardian when the program administers the medication because the person cannot self-medicate. There might be situations, such as in placement services, where the requirements of MAP do not apply, but the person still receives support from the home provider in taking his or her medication. Where the home provider gives the medication, the requirements of 5.15(4) apply.

If the person is able to take his or her own medication, then the requirements of 5.15(4) do not apply. If the person lives at home and the family gives the medications, these requirements, likewise, do not apply. Further, if the person attends a work/day support and the medication is administered by the residential provider, then the onus of ensuring that there is a plan in the ISP falls to the residential provider.

Even when a provider does not have to adhere to the requirements of 5.15(4), they still have other responsibilities with respect to individuals' medications in the context of the person's overall health and wellness. For example, even if a person does not take medications at work, the agency providing those supports has an affirmative responsibility to be knowledgeable about medications that the individual is taking on a regular basis and the side effects of those medications. Knowledge of the medications may be critical in providing effective, appropriate and safe supports that meet the individual's needs. These would be reviewed and rated in Outcome 5.3 (People maintain good health).

Finally, in situations where the provider does not administer medications to control or modify behaviors, they may still have a role in aspects of the person's treatment. Indeed, the provider may collect data on specific behaviors or even assist the individual in providing information to the treating psychiatrist. The level and type of involvement would be defined on a person-by-person basis and would usually, but not always, be articulated in the individual's ISP. Where the provider has this role, it can be recommended, although not required, that a medication treatment plan be developed. The provider should also take appropriate action where there is no court order for any individual who is taking antipsychotic medications and is not "capable in fact of giving informed consent to such treatment." This involvement still does not require that the provider, who is involved in the treatment, but is not administering the medications, comply with the requirements of 5.15.

Restraints

Indicators D and E are always answered if the individual has been restrained in the past year or if there is a protocol for the use of restraint under certain circumstances.

Supports and Health-Related Protections

Indicators B, C, D and E are always answered for a support or health-related protection. Even though the primary intention of these interventions is to enhance or protect the individual's health or well being, appropriate safeguards need to be in place when they are being used.

Interventions used for the safety of the individual or others

Indicators B, C, D and E are always answered for interventions that are not part of a behavior plan but are used for a variety of reasons, usually related to safety. Some examples could include having a buzzer on the door to alert staff of a person who will dash out into the street; locking the refrigerator for a person with Prader Willi Syndrome; or keeping a person in staff's sight at all times when in the community because he or she may be inappropriate with others.

Interventions such as those described above are not specifically designed as treatment to change behavior and therefore are not included as part of a behavior plan. These interventions are usually designed to protect the person from harm, either to him/herself or others. Generally, these interventions should be included in the individual's ISP or in a Risk Management Plan. As a part of the ISP it should be demonstrated that the interventions are the least restrictive and assist the individual in reaching his or her goals and, therefore, reducing the need for the intervention over time.

Questions often arise as to whether these interventions must be reviewed by the human rights committee. Certain interventions, even those used to provide a safe environment for the individual, must always be sent to the human right committee. They are as follows:

- Any limitation of movement (restraints, supports and health related protections, holds implemented in a behavior modification plan);

- Restrictions on personal possessions and funds; and
- Any strategy that denies or restricts other people from visiting with the individual.

While it is not required, it can be recommended that the human rights committee review other safety-related interventions.

It is possible that other individuals, who do not need the intervention, might be impacted by the use of the intervention. Where this occurs, the provider should seek agreement from the other affected individuals. While the surveyor might not always see written agreement, the agency needs to demonstrate that they have sought agreement from the individuals or guardians. Finally, where possible, the provider should seek ways to minimize the effect that the intervention has on other individuals.

Court ordered restrictions

Indicators B, D and E should always be answered when there are Court ordered restrictions. At the outset it is important to understand that court imposed restrictions are directed to the individual, not the provider or DMR. It is, therefore, the person's responsibility to comply with the conditions placed upon him or her by the judge. In most instances a specific intervention is not articulated, rather, more usually it is a restriction that prohibits the individual from doing something as a condition of probation. As an example, the condition may be that the individual is prohibited from visiting with children at a school. The individual's role is to comply with the condition. The provider's role is to develop the strategies and interventions that will support the individual in his or her effort to comply with the restriction. So, for example, the provider may put a buzzer on the front door or keep the individual in sight when he is in the community or support him to stay away from children at a school. While the court's order is not subject to the DMR regulations, the provider's strategies to assist the individual must conform with the regulations, as applied to the specific strategies that are being employed and to the extent they are not inconsistent with the court order. In cases where the court prescribes the actual intervention, the judges ruling supersedes the DMR regulations. In these instances, the surveyor (and provider) should expect to have the details of the restriction in writing from the court.

GATHERING THE NECESSARY INFORMATION

Surveyors gather a wealth of information in order to evaluate outcome 1.3 much of which is incorporated into the Interventions and Restrictive Practices Worksheet. Following are some additional probative questions meant to supplement the questions that surveyors ask to obtain the information they need to rate outcome 1.3:

A) What steps does a provider take to understand an individual's behavior in order to determine what interventions to use?

1) Does the organizational culture support an open exchange of ideas?
2) Does the organization review significant aspects of the person's history, behavior, relationships and health to

determine possible causes for his or her behavioral problems?

3) Does the organization listen to what the person is communicating through his or her behavior?

B) How does the physical environment facilitate/support positive behavior?

During the course of the walk through in the home or work place, the surveyor should look for environmental factors that could be potentially restrictive. These could include such things as door/window alarms, locked rooms, cabinets or refrigerators.

1) What is staff understanding of the purpose of such an intervention (e.g., part of behavior plan; for safety of individuals/others/staff; staffing shortage)?
2) How long has the intervention been used?
3) Is there awareness on the part of individuals in the home that a potential restriction is present?
4) Does the intervention impact on the quality of life of others living in the home and how is any negative impact mitigated?

As well, the surveyor should look for ways that the provider has shaped the environment to assist the person in having more socially appropriate behavior (e.g., painting the individual's bedroom in colors that he finds especially calming).

C) Are staff trained to implement interventions?

1) Does staff have a shared understanding of the intervention, and are they clear about what responses are called for under specific circumstances?
2) What specific training has staff received with respect to implementing an intervention?
3) Are staff supervised and monitored with respect to proper implementation of an intervention?
4) Does staff feel comfortable carrying out the intervention?
5) Does staff know who to go to for help if needed?

D) What is the nature and extent of clinical oversight?

1) Who is providing clinical oversight?
2) How consistent and frequent is the nature of the oversight?
3) Does the oversight involve direct observation of staff and individuals?
4) Does the clinician with responsibility for oversight review data regularly?
5) Does the clinician modify the plan, if needed, as a result of observation and data analysis?

6) If able, is the individual involved in self-reporting on changes in his or her behavior?

E) What if there is court involvement?

1) If there is a court order, is its parameters understood by the organization?
2) If the court order gives responsibility for development of the plan and restrictions to the provider, are the appropriate safeguards being followed?
3) Has appropriate clinical consultation been sought to assist in the development of the intervention?

RATING OUTCOME 1.3

After gathering all pertinent information, the surveyor must integrate all the information and weigh its importance in determining how to rate the outcome. The following are a set of guidelines to assist surveyors in determining the presence of the outcome. The guidelines are directly related to the specific indicators in outcome 1.3:

Indicator A, "all interventions are the least intrusive and are based upon people's unique needs" must be answered Yes in order to rate the outcome Achieved.

- A surveyor may apply the "point in time" judgment to this indicator. For instance, an individual may be new to a service and the provider may be in an assessment and fact-finding stage with respect to what will work best to support an individual. They may, therefore, during this transitional period, be employing a behavioral intervention, which may not in the long run, be the least intrusive. It is, however, for that person, at that point in time, the least intrusive or safest approach, absent more definitive information. Therefore, the surveyor can answer, "Yes" to this indicator.

Indicator B, "all interventions are included in a written plan" must be answered "Yes" in order to rate the outcome Achieved.

- While a surveyor may be reviewing an individual at a transitional period of time, and plans may be interim in nature, there is never a time when the absence of some form of a written plan is acceptable. This indicator, therefore is not subject to a point in time approach, and must always be answered "Yes" in order to give the outcome an achieved.

Indicator C, "People, or their guardians, knowingly and voluntarily give consent and have the opportunity to refuse or withdraw approval", will in almost all circumstances need to be answered "Yes" in order to rate the outcome Achieved.

- Under very limited circumstances the indicator may be answered No and still result in an Achieved rating for the outcome. This is due to the point in time that the surveyor is reviewing the support. An individual, for example, may have a plan in place on an emergency basis due to the threat of imminent or actual harm to himself or others, which precludes gaining all the necessary approvals in the usual timeframes In this situation, while the answer is No to the indicator, the overall outcome can still be an Achieved.

- If the individual is under a court ordered restriction, the indicator may be answered No and the overall outcome can still be an Achieved

Indicator D, "safeguards ensure a thorough review and approval process when needed", will in almost all circumstances need to be answered Yes in order to rate the outcome Achieved.

- It may be answered No in very limited circumstances and still be rated an Achieved. This is due to the point in time the surveyor is reviewing the service. For example, an individual may have an intervention on an emergency basis, with peer review and human rights committee review scheduled within an acceptable time frame. Even though the review has not occurred at the time of the survey, as long as it is scheduled to occur, the surveyor can rate the indicator No, but the outcome Achieved.
- If the individual is under a court ordered restriction, the indicator may be answered No and the overall outcome can still be an Achieved.

Indicator E, "all interventions are safely, accurately and consistently implemented", must always be answered Yes in order to rate the outcome Achieved. It is not subject to a point in time assessment. A surveyor should always be able to determine if the provider implements interventions safely and consistently regardless of what stage in the implementation of the plan the surveyor is doing the review.

A GUIDELINE FOR UNDERSTANDING AND RATING OUTCOME 3.3 PEOPLE HAVE RELATIONSHIPS

Introduction: Distinction between outcomes in Quality of Life Area #3 - Community and Social Connections

Quality of Life area #3 looks at the many and varied ways that people can connect to other people and their community. As such, there is a certain amount of overlap between the 3 outcomes we look at in this area. Despite this overlap and a certain continuum, which the outcomes reflect in the lives of all individuals, there are some clear distinctions that can be made particularly between 3.3 (People have relationships) and the other 2 outcomes, 3.1 (People are integrated into their community) and 3.2 (People are connected to their community). To begin with, 3.1 looks at how physical integration into one's community and the use of the same resources as everyone else, serves as a stepping stone to bringing people with mental retardation into contact with others. This contact can serve to kindle acquaintances, serve as a means to assist individuals to have natural and appropriate interactions with others, and may lead to greater involvement in community life. Outcome 3.2 takes that physical integration a step further and explores how individuals are supported to take part in activities that may bring them in closer touch to their own unique gifts as well as helping them to be recognized as valued members of a community with something to share. The emphasis on this outcome, even though it may lead to friendships and deeper relationships, is on exploring interests and different roles that a person can play in his or her community. While these involvements and connections usually lead to acquaintances and recognition of individual worth by a broader community, it is when these acquaintances move beyond the focus on the interest or activity to a focus on the friendship and reciprocal nature of a relationship, that they cross over from 3.2 to 3.3.

While surveyors must be careful not to impose their own judgments on the value of different types of relationships, there are certain assumptions that can be made as a starting point for reviewing this outcome. Most important is the basic premise, that all individuals, with rare exceptions, are social creatures who enjoy and benefit from contact with others, whether or not they are able to verbally express that need. A person's "label" therefore should not be a rationale to conclude that a person is not interested or cannot benefit from relationships with others.

Guidelines for interpreting Indicator A: People are supported to maintain and enhance relationships with family, friends and co-workers

- This indicator explores both existing and pre-existing relationships an individual has. It is expected, with only rare exceptions, that all individuals come to a provider with a "history" which includes a variety of relationships from the past. In evaluating this indicator, the surveyor will look at relationships with family, friends and co-workers, but it does not necessarily follow that all of these relationships must be present in order to be able to say yes to this indicator. What the provider does will depend largely on the past and current relationships the individual has. What is expected is that the provider will make intensive efforts to connect (or re-connect) individuals

with people they have relationships with currently or have had relationships with in the past that the individual, or those that know him or her well has identified as meaningful.

- For many individuals, existing relationships with family, friends and co-workers may be among the deepest, most long lasting and trusting relationships an individual has. Providers need to be sensitive to the depth and intensity of these long-term relationships and be prepared to nurture and support them.

- When looking at indicator A, no distinction or different value should be placed on whether the relationship is with a disabled or non-disabled person.

- Relationships with staff paid to support an individual, no matter how positive, should never be viewed as a friendship freely given, as it is the staff person's responsibility to support that person. If a former staff person retains a friendship with an individual even after they are no longer paid to support that person, that relationship may be considered when looking at indicator A.

- For different reasons, certain existing relationships may take precedence over others. In evaluating this outcome, therefore, it is important to look at what is important to the person being surveyed, how the provider understands the nature and depth of the connection and how the provider operationalizes this for the individual.

- In only very rare circumstances would a surveyor find an individual who has no existing or pre-existing relationships that could be supported and maintained. Even in this situation, however, the surveyor would look for the nature and extent of the effort on the part of the provider. It is possible that there has been concerted effort on the part of the provider but that there are no existing relationships or that the individual is very clear that they don't want existing or pre-existing relationships maintained. In this rare situation, the indicator can be answered, yes, because the provider has made all the necessary effort.

- When reviewing "placement services," it is important to know that there is a difference between the home provider's friends and the individual's friends.

Guidelines for interpreting Indicator B: People are supported to develop new friendships

- This indicator focuses on a provider's efforts to assist people to develop new friendships with both disabled and non-disabled people. While acquaintances may evolve out of the utilization of community resources and involvement in different activities or groups, the existence of acquaintances or friendly interactions should not be confused with friendships. Friendship implies a reciprocity, sharing and trust between two individuals which would not be expected of mere acquaintances.

- Many individuals have cordial and friendly interactions with people with whom they come in contact in the community. For instance, an individual may have their hair cut by the same barber every month. While there may be cordial conversations

during this period of time, the barber is essentially a service provider and a fee is being exchanged for the service provision. This type of relationship should not be mistaken for a friendship. If, however, the barber were to invite the individual to his/her home for a holiday, or out to a ball game, the relationship is clearly moving beyond the confines of the barber's service provision role and into the realm of a friendship.

- There are no circumstances when the surveyor can assume that developing new relationships is unimportant. All situations must be viewed on an individual-by-individual basis. For instance, someone might conclude that an individual experiencing a catastrophic or terminal illness would not have a need for new relationships. On the other hand, there are people who do reach out to others, through support groups or other mechanisms, during major illnesses.

  When evaluating this indicator, surveyors should look at the following areas:

1. Is the staff supporting a range of friendships with both disabled and non-disabled individuals?
2. Is there a culture within the agency that places a high value on the importance of friendships?
3. Does the staff recognize and capitalize on opportunities to encourage and support new friendships?
4. Does the staff promote, foster and nurture friendships?
5. Are the efforts to support new friendships individualized?
6. Does the staff recognize that even failed efforts can be opportunities to teach individuals about friendship?
7. Does the staff reassess how long it has been trying a certain strategy, and make modifications when necessary?
8. Does the staff teach the individual the reciprocal nature of friendships and how that can get operationalized?
9. Does the staff look at how friendships change and evolve over time?

Guidelines for Interpreting Indicator C: People are supported to explore, define and express their need for intimacy

- Essential to understanding and evaluating this outcome is the basic assumption that all human beings intrinsically have a gender identity and a sexual nature and are capable and worthy of intimacy. While this may manifest itself in many different ways ranging from knowing one's own feminine or masculine identity to romantic and intimate relationships, it is expected that the provider will recognize the full range of possibilities in every individual whom it supports.

- This indicator explores the full forms of expression of this side of human nature, and more particularly how the provider is positioned to support individuals to learn about this side of themselves. Both the surveyor and the provider must recognize that this indicator covers the full scope of self-knowledge and relationships including gender identity, orientation, self-expression, romantic and physical encounters and relationships. Where on the spectrum a person is, and consequently what supports a

provider must offer, will vary and is dependent upon an individual's desires, needs and level of self awareness.

- It is recognized that some long term friendships and relationships with family members can be intimate in nature. However, those relationships should be reviewed under indicator A. Indicator C should be reserved for reviewing the supports in place to assist an individual to explore his or her sexual nature and its various forms of expression.

- Exploring this area during the course of an evaluation is not intended to discover the most intimate details of an individual's private life. In fact, if an individual chooses not to discuss this area with a surveyor, that decision should be honored. This is because the emphasis is not on the individual's behavior, but rather on the provider's behavior, practices and supports. The goal of a surveyor's questions in this area should be aimed at determining how well the provider knows the individual and what affirmative and proactive supports and teaching strategies are in place to assist individuals to understand themselves and to make decisions that are healthy and safe.

Suggested questions to ask concerning indicator C

Surveyors have sometimes expressed a certain level of discomfort in exploring this area with individuals and providers. Again, what must be remembered here is that the intent is not to discover the details of an individual's actions and choices in this area, but rather to gain a clear sense of the provider's knowledge, skills, and sensitivity and their ability to guide, support and assist individuals in this critical area of their lives. Not to do so would be shirking our and the provider's responsibility to assist people to make informed, safe and healthy choices in their lives.

The following are some suggested questions to assist surveyors in framing the issues and eliciting helpful information. These questions are not intended to be all inclusive, and should be tailored to the individual you are surveying:

Questions for the house manager or other supervisory staff:

1. How do you approach issues of intimacy and relationships, such as sexual expression, privacy?
2. Do you have any policies or practices in this area? What do they say?
3. How do you share these policies with staff?
4. How do you support staff to be sensitive and knowledgeable in this area?
5. How do you begin to help people to understand their sexual and gender identity?

Questions for direct care staff:

1. How do you support people to feel good about themselves when they leave the house in the morning?

2. Are people supported to "check out" how they look? (Are they encouraged to look in the mirror?)
3. Is ___ dating or have an interest in someone?
4. Has ___ expressed an interest in dating?
5. Have you explored _____'s interest in dating?
6. How would you assist ____ to approach someone they were interested in?
7. Where do you see this person going in this area of their life?
8. What would you do to take it to the next step?

Questions for individuals:

1. Are you in a romantic relationship now? (or) Do you have a boyfriend or a girlfriend? (If yes, continue. If no, proceed to Section 2. Do you go on dates together? Visit each other at home? Does your staff help you to get together? For example, does someone help you to use the phone to invite her/him out, make reservations find out about movies, etc? Do they provide or help you to arrange transportation? Do they help you prepare a romantic dinner and/or make sure you have some private time with your boy/girlfriend if you want it? Proceed to section 3;
2. Are you interested in meeting someone you could spend time with/go on dates with? What are some of the places you go or activities you do where you might be able to meet someone? Does your staff help you to think about places to go or help you to get there?
3. Have you had opportunities to talk to other people about dating, relationships, intimacy, being close or sexual with someone? (the language you use will depend on the person you are interviewing) Was this in a class with other people or with your partner/boyfriend/girlfriend or alone? Was it helpful to you? Would you like to have more opportunities to talk to other people about these things/topics/ideas?
4. If you are interested in meeting someone, is there anything that gets in the way of you doing that?
5. Do staff or other people help you to work through any difficulties you might have?
6. If you are going out on a date, or to a dance where you hope to meet someone special, are there certain things you like to wear or do ahead of time that make you feel and look really great? For example, some people like to wear cologne/sport coat/tie/certain pair of pants/dress/make-up/get their hair done, etc.
7. Does your staff do things to help you get ready? Can you explain what those things are?
8. Do you like the help they give you?
9. Are there things they do that are not helpful? Can you explain what those things are?

Rating the Outcome

When rating this outcome, it is important to remember that despite a provider's best efforts, the result may not always be an array of deep friendships and relationships. There are certain "givens", however, which must be present as a foundation to looking at this outcome.

1. There must, first and foremost, be a respect and acknowledgment of the capacity and potential for individuals to form relationships.
2. There must also be recognition that all individuals have a sexual nature which must be expressed, even if those expressions may be limited due to the person's life circumstances at the time of the review.
3. Without these two foundations, the outcome cannot be achieved.

The commitment to the importance of relationships in an individual's life, combined with the nature, intensity, consistency, and creativity of supports, can be evaluated effectively. It is in fact, what forms the basis of the rating for this outcome. All three indicators in this outcome are worded in terms of "support provided." **Therefore, all 3 indicators must be answered yes, in order for the outcome to be achieved**. As with all other outcomes in the survey tool, the surveyor should refer to the decision tree with respect to "choice" and "point in time" issues.

GUIDELINES FOR REVIEWING PROVIDERS' EFFORTS TO SUPPORT PEOPLE TO DEVELOP AND ACCOMPLISH THEIR GOALS

Introduction

Assisting individuals to develop and accomplish their goals is one of the most important activities in which a provider participates. Through their day to day knowledge and involvement in the lives of individuals they support, staff of provider agencies are well positioned to be sensitive to what is important in a person's life and what strategies will be most successful in assisting a person to achieve their stated desires. It is also one of the most challenging responsibilities a provider has, for in order to assist people to achieve their dreams, a provider must first know what the person wants. Finding out what is important to a person is not an easy task, particularly for individuals who may not be able to articulate their wishes. It involves using a repertoire of skills and strategies and an exquisite sensitivity to the individual. Concurrently, it is equally challenging for surveyors when reviewing the provider's supports, to determine the quality of the strategies it uses to assist people in this critical area of their lives. The following guidelines provide assistance to surveyors as they review and rate outcomes 2.3- "People are the primary decision makers in their lives" and 4.1- "People accomplish their goals."

Goal Development and Goal Accomplishment

The survey and certification tool looks both at how providers are supporting individuals to develop their goals as well as how individuals are supported to achieve their goals. This review is accomplished and rated in two different outcomes, 2.3. (People are the primary decision-makers in their lives) and 4.1 (People accomplish their goals). While rated in two different outcomes, there is an integral connection between the two processes and the differences between the two may be subtle. In reality, the process of goal development and accomplishment is a continuous cycle, an unbroken circle. Individuals engage in various activities to assist them in setting goals. They accomplish goals and their successes, failures and experiences help them to revisit and establish new goals. While this seamless connection between goal development and accomplishment is an important aspect of an individual's life, it can sometimes pose a challenge for surveyors reviewing a provider's supports.

Perhaps the simplest way to distinguish between the two outcomes is to consider "planning" versus "doing" activities. Activities aimed at assisting an individual to plan, define and shape his or her goals should be rated under 2.3, while intentional activities and actions designed to assist a person to achieve his or her goals should be rated under 4.1.

What is a goal?

Prior to determining whether staffs are supporting an individual to develop his or her goals, staff must be clear about what a goal is. Simply stated, a goal is defined as anything that is important in the life of an individual. Asking individuals what is

important in their life, what their dream is, or what they want to do, is synonymous with asking them what their goals are. Goals can be large and represent a total vision for an individual's life, or they can be small and time limited. Defining one's career path and owning a home are examples of long range goals, while going on a vacation is an example of a smaller, more time limited goal. What is a goal for one person may not be relevant to another person. What makes a goal important is its relevance and importance to the individual. No goal, no matter how trivial or seemingly unattainable, should be negated. Rather, goals should be viewed as the basis for planning and action in support of a person. There may be several stages or activities an individual goes through in order to achieve a desired goal. While these steps are important stepping stones towards goal achievement, they should not be confused with the goal itself. For example, trying out several different job sites or attending to a particular task for a certain time period are not goals. Getting a job, is.

Goal Development – a dynamic and on-going process

It is important to bear in mind that development of one's goals is not a one time event, but rather a fluid, changing and dynamic process. Many of the individuals that providers support may not have had opportunities to explore and define their goals. Their experiences may be limited due to their life circumstances and therefore defining what is important to them will be accomplished through exposure to a variety of activities and experiences, which occur over time and on an on-going basis. Therefore both providers and surveyors should neither look for nor expect that goals will be developed in one particular manner at one convenient time per year. Rather, they will evolve and may come about at unanticipated times in unexpected ways. Further, goals articulated and developed at one point in time may change and providers attuned to individuals recognize the need to remain flexible in supporting people to shape their vision and goals.

Goal development processes

Providers assist people to develop their goals in a variety of ways. It is important to keep in mind that there is no one mechanism that fits all individuals and that in fact, several different approaches are typically used simultaneously to get at what is important for a person. While the annual Individual Support Plan (ISP) is clearly one of the more formal ways in which a provider establishes goals with individuals, it should not be viewed as the only mechanism and in reality, it is usually the end product of an ongoing and dynamic process that occurs throughout the year. An important component of any planning process, is a clearly articulated and rich vision statement. Without this foundation, it is doubtful that goals and actions, which follow, will have real meaning for the individual.

Regardless of the process a provider utilizes, surveyors should expect to see a deliberate and intentional set of actions that have as their focus, the setting of goals. Such actions might include the following critical components:

1. Someone or several people in the agency who know the individual well, are invested in that person and are especially tuned into what they like and dislike,

2. A clear mechanism to capture information regarding a person's desires and dreams. There are a variety of ways that this can be done, including but not limited to:
    - Talking with and listening to the individual's stated or non-verbalized wishes,
    - Supporting the person to try new things to see what the person is good at or what motivates him or her,
    - Helping the person to prioritize, even recognizing that some things may take a back seat,
    - Being sensitive to unexpected events in the person's life,
    - Talking to individuals who know the person well,
    - Developing "vision" statements with the person,
    - Recording reactions to experiences and activities,
    - Assigning specific staff to observe the individual's reactions to experiences,
    - Using videos, logs, photo albums.
3. A clear way to share information about what is important to an individual so that all relevant people in the provider agency are attuned to the person's goals. Examples of how information might be shared include, but are not limited to, staff meeting notes, logs, progress notes, and plans,
4. An ability on the part of the provider to clearly articulate how it develops a vision and goals with an individual.

Goal Accomplishment

Assisting people to accomplish their goals is a creative, intensive and ongoing effort on the part of providers. Once developed, a surveyor should expect to see a variety of very deliberate actions, supports and activities designed to assist an individual to achieve his or her goals. There should be an integral connection between what the person is doing and their articulated goals and vision. It may also necessitate the provider being creative, and even seeking out non-traditional means, in an effort to support people to accomplish things that are important to them. Helping people to set priorities is another important role for the provider. Not everything is of equal importance and the provider may need to put the more energy into things that are most meaningful to the person. Surveyors should also expect to see flexibility and a willingness on the part of the provider to make mid-course corrections if and when an individual's goals change, or if the strategies are not working. This does not imply that surveyors will see the "end product" when they arrive for a review, but they should expect to see a deliberate set of actions and a staff mobilized to act on and support an individual in achieving his or her goals.

Helpful hints for surveyors

As stated earlier, developing and accomplishing goals with individuals and evaluating how well a provider is doing in this critical area is not an easy task. Below are some suggestions for how surveyors can review this area:

- Surveyors may want to start with getting an overall sense of what individuals are interested in for their whole life, and then look to see where in any planning

document, whether it is an ISP, whole life plan, or other document those interests and dreams are reflected.

- Surveyors may also ask what successes a person has had. Both the person and his/her staff are often eager to speak about such things. These success stories will give the surveyor a sense of where the person has been and where they are going. Staff may not always be able to articulate something as a "goal." They can, however, speak eloquently about an individual's achievements, which will oftentimes lead you back to both formal and informal goals.
- Surveyors may also talk to staff about the things a person is working on as a way of leading back to the goals. The surveyor may also ask where the struggles have been and how they are working through them. When interviewing staff, the surveyor may want to focus on learning what staff see as important in the person's life and how they figured this out. It would also be important to find out how they communicate this information to other staff.
- Look at the provider's myriad of formal, informal, written and verbal processes.
- Surveyors may want to start with the ISP, but that document should be viewed as a jumping off point, not an end in and of itself. The ISP cannot be expected to contain every goal a person wants to achieve, and so it should be looked at in combination with other processes. While surveyors are not "rating " the ISP, they should expect to see a clear and rich vision statement, which is a reflection of the individual's hopes and dreams, as well as a set of meaningful goals directed at assisting an individual to achieve his or her vision.
- Look at how the provider involves the individual in the process. Are they actively engaged in listening to the person and in finding out what's important to him or her? How do they elicit information about what a person may want? Who do they speak with, in addition to the individual, to get at this information? For example, do they confer with the family or even use "peer to peer" discussions?
- How are assessments and evaluations integrated into the goal development process? Does the provider use "situational" assessments as a way of seeing what interests and motivates the individual?
- Look at how the provider integrates feedback from the individual to change, refine or reshape goals and dreams.
- Be careful to look at the goals in the context of the history of the individual. A surveyor should be able to determine whether a goal has been continued for several years with no appreciable results. Conversely, what might look like a very small insignificant aspect of a person's life, may in fact be the culmination of several years of work and progress.
- When speaking to the individual ask about hobbies or other things they like to do. It is a way of seeing if there is a match between the person's goals and what really interest him or her.

Rating Outcome 2.3

"People develop their personal goals" is one indicator used to rate outcome 2.3. (People are the primary decision-makers in their lives). However, it is a foundational one. If an individual has not developed their goals, it would be difficult to conclude that they are controlling other important decisions in their lives. Therefore, a surveyor must be able to

answer "yes" to indicator A in 2.3 as a pre-requisite to rating the entire outcome "achieved."

Surveyors will sometimes say that they see goals being achieved, but that the individual does not necessarily subscribe to the goals, or that the goals are limited in scope and not a reflection of significant exploration or exposure to various options. In these situations, while the goal may be being achieved, the goal development process is missing certain critical components, and therefore the surveyor cannot conclude that the individual has been truly engaged in the goal development process.

Rating Outcome 4.1

When rating Outcome 4.1 it may be more useful to start with indicator B, "There is a match between what people are doing now and what they want to do in the future." The surveyor should expect to see a series of deliberate, well thought out actions that are connected to and assist an individual to achieve his or her goals. So, if a person has a goal of working out of doors at something relating to gardening or landscaping, you would not expect them to be sitting and doing bench work as their primary work effort. In this example, there is not a match between what the person is doing and what their goal is. Indicator B looks at how individuals are actualizing their goals. It is the "doing" indicator. A surveyor must be able to answer, "Yes" to indicator B in order to rate the outcome "achieved."

Indicator A looks more at how staff is positioned to support achievement of an individual's goals. It looks at whether staff's actions and support strategies are tied into the individual's goals. Indicator A must also be answered, "Yes" in order to rate the outcome "achieved."

Indicator C asks the question of whether individuals have access to needed resources in order to accomplish their goals. While resources can be interpreted very broadly, for purposes of this indicator, it is intended to refer to ancillary and clinical supports tied to individual need, not to the overall staffing or financial resources of the agency.

RESPITE INTERPRETIVE GUIDELINES

1. **Rating the Respite Service**
   A. Complete a "yes/no" response for each applicable indicator for each individual in the sample. If not enough information is available to do a "yes/no" response, a "not applicable" response may be applied to that outcome. The following outcomes do not apply to respite:
      2.3 - People are the primary decision-makers in their lives.
      3.2 - People are connected to their community.
   B. Print out the initial respite rating sheet with the tallies of the "yes/no" responses for each applicable Indicator.
   C. Using the tallies of the "yes/no" responses as a guide, one cumulative rating is assigned to each applicable outcome in the tool.

2. Notice of Immediate Action Required

As with any other survey, Action Required or Immediate Jeopardy notices may be issued. The QE Specialist will follow-up to ensure the situation is corrected.

3. Results of the Respite Review

A. The format for presenting the results of the respite reviews is identical to the residential and work/community supports. The findings specific to the respite services will be presented in the "comments" section of each quality of life area in of the Provider Report. Following the comments for respite there may be Areas Needing Improvement, Suggestions for Service Enhancement, and Commendations.
B. While not impacting the ratings in the Quality of Life Areas, information from the survey of respite services will be used in rating the Outcomes for the Organization.
C. Issues in any of the flagged outcomes are also listed in the Safeguards Summary by location.

4. Follow-up

A. There is follow-up on all Action Required or Immediate Jeopardy notices.
B. There is follow-up on all issues identified in the Safeguards Summary in Quality of Life Areas #1 (Rights and Dignity) and #5 (Personal Well-Being).

5. Guidelines for the tool as it applies to site-based respite services

LICENSING OUTCOMES

Quality of Life Area: Rights and Dignity

Outcome 1: People are valued

Indicators:

A. Interactions are respectful of people.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

B. People are supported to identify themselves as adults.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

C. People are supported to take pride in themselves and their surroundings.
Application: Applies to both planned and unplanned respite.
Guidelines: While individuals may not have control over their surroundings, the agency creates a valued, enhancing environment in the respite center. Further, individuals while at respite, are supported to take pride in their attire and personal appearance.

D. People live and work in settings that are typical of other members of the community.

Application: Applies to both planned and unplanned respite.
Guidelines: While the respite center may blend into the community it may possess features that do not always resemble a "home." The design, layout and location will be dependent upon the needs of the individuals served. While people may do things that they would typically do while at home such as answer the phone and door, this may not always be done (or encouraged) at respite since it is not the individual's home.

Outcome 2: People's Rights are Affirmed

Indicators:

A. People and/or those supporting them understand individual rights.

Application: Applies to both planned and unplanned respite.
Guidelines: In respite it is most important that staff have a good understanding of individual rights. The role of the provider in teaching individuals about their rights is more targeted to their rights while in the respite service. Individuals receiving planned respite should be educated about their rights at respite in a manner that is compatible with their learning style. This should occur before or at the beginning of their respite stay. Individuals receiving unplanned respite may be educated about their rights after the initial crisis of receiving respite occurs. Families and guardians are provided with information outlining people's rights as they apply to respite.

B. People's rights are exercised in their everyday lives.

Application: Applies to both planned and unplanned respite.
Guidelines: Individuals have reasonable access to basic goods and services. While it is unlikely that individuals would have a telephone in their bedroom, every effort should be made to afford privacy to individuals when making personal phone calls.

Outcome 3: People's rights are protected

Indicators:

Application: Always applies, using the following criteria for rating:

1. Indicator A is always rated for everyone. The surveyor should look at whether the individual is supported through only positive means or any interventions are based on an individual's unique needs and consistent with the person's learning style. "House rules," where they exist, may not be a result of consensus by all the respite houseguests because respite is not a permanent home and individual stays are considered temporary. Nevertheless, house rules, where they exist, should not abridge individuals' rights (e.g., consequences for specific behaviors, predetermined bedtimes).
2. There may be some circumstances where the provider needs to develop a plan quickly especially in unplanned situations where there is a need to stabilize the

individual. In these situations, the entire outcome and all the indicators (A - E) apply.

3. There may be situations where the respite provider is implementing a plan that has been developed elsewhere. In those instances all the indicators apply with the respite provider's role being to ensure that all necessary reviews had been completed.
4. In some situations an individual may come to respite from their family home with a particularly restrictive intervention. Even in these circumstances a professional develops the plan and staff are trained to implement the intervention. If the plan has not been reviewed, the head of the provider can still implement the plan until the needed reviews are conducted, if the intervention is designed to protect the health and/or safety of the individual (exceptions: Level II plans cannot be implemented without the physician's review). The provider should only implement an intervention that has been developed by a professional**.**
   Guidelines: See indicators below.

Indicators

A. All interventions are the least intrusive and are based upon people's unique needs.

Application: See "Application" above.
Guidelines: The provider may not know the individual well enough to formulate a plan that is ultimately the least restrictive or intrusive. It may be the least intrusive at the point in time that the survey is being conducted based upon the provider's current knowledge of the individual.

B. All interventions are included in a written plan.

Application: See "Application" above.
Guidelines: None needed.

C. People, or their guardians, knowingly and voluntarily give consent and have the opportunity to refuse or withdraw approval.

Application: See "Application" above.
Guidelines: None needed.

D. Safeguards ensure a thorough review and approval process when needed.

Application: See "Application" above.
Guidelines: None needed.

E. All interventions are safely, accurately and consistently implemented.

Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

Quality of Life Area: Personal Well Being

Outcome 1: People are safe at home and work

Indicators:

A. People's home and work place are safe, secure and in good repair.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

B. People and their supporters know what to do in an emergency.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

C. People can safely evacuate from their home or work place in an emergency.
Application: Applies to both planned and unplanned respite.
Guidelines: In a respite situation, the onus of responsibility for assuring the safety of individuals in the event of an emergency requiring evacuation rests with the staff. While the individuals coming into a respite home may be made aware of the evacuation procedures, they cannot be expected to take primary responsibility, since the respite home is only a temporary situation. Staff must be trained in evacuation procedures and be familiar with all the needs of the individuals living in the home at a given time. Fire drills may not be conducted with individuals, but staff must practice drills to ensure that all staff on all shifts knows the evacuation procedures.

D. There are adequate supports for people to be safe in their home and at work.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

E. People use materials and equipment safely.
Application: Does not apply.

Outcome 2: People are free from harm

Indicators:

A. Supports are in place if people make decisions that put them at risk.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

B. Immediate actions are taken to ensure people's safety.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

C. Actions are taken to correct the situation when people have been mistreated.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

D. Steps are taken to prevent the situation from occurring again.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

E. People know how or have support to report a situation where they feel they are being or have been mistreated or harmed.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

Outcome 3: People Maintain Good Health

Indicators:

A. People are supported to have a healthy lifestyle.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

B. People are supported to be active participants in their health care.
Application: Unlikely to apply in planned respite; may occur in unplanned respite.
Guidelines: In an unplanned respite service the individual may be involved in some new treatment decisions which may involve use of medications or other interventions. For a planned respite, other than an emergency, it is unlikely that a situation would arise requiring the active involvement of an individual.

C. People have needed routine and specialized health care services.
Application: Applies to both planned and unplanned respite.
Guidelines: In most instances there is not a need to arrange for routine or specialized health care supports based on the assumption that individuals have their own health care provider. The respite provider's role is to know the person's health/care provider in case he/she needs to be contacted and to have an emergency response plan in place should the need arise.

D. Supporters are knowledgeable about people's health care needs.
Application: Applies to both planned and unplanned respite.
Guidelines: In an unplanned respite situation, the provider may not have the necessary health care information when the person first arrives. In this situation the provider has systems in place to quickly assess individual health care needs and to identify any issues. The provider can access health care evaluations as needed, and has the resources to develop an adequate record of the person's health history and needs during his/her stay.

E. People's medications are given properly and as prescribed by the practitioner.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

Outcome 4: People's funds are safeguarded

Indicators:

A. People receive the support and/or education they need in managing their financial resources.

Application: Applies to both planned and unplanned respite.
Guidelines: During intake, the provider learns about the individuals' ability to handle their own money. This indicator is rated only where support is provided. In a longer term stay, if the provider actually takes over the management of an individual's funds, there would be a plan for shared and delegated management funds, although one would not be likely to see a "training plan." Also, if the stay is longer and the individual pays "charges for care," those regulations would apply.

B. People's funds are managed properly and with their consent.

Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

QUALITATIVE OUTCOMES

Quality of Life Area: Individual Control

Outcome 1: People are understood

Indicators:

A. Supporters understand what people are expressing.

Application: Applies to both planned and unplanned respite.
Guidelines: Staff need to make every effort to obtain information from the referral source on the person's communication style and to apply that information to a basic understanding of what people are communicating. Provider's have access to resources (internal or external) to anticipate people's means of communication, ensuring that individuals' basic communication needs are meet shortly after they begin their respite stay. As a part of intake, the provider learns about individuals' communication strategies, devices etc. so that supports can be incorporated into the respite visit.

B. Supporters use people's primary means of communication.

Application: Applies to both planned and unplanned respite.
Guidelines: In the case of a planned respite stay, the provider should make every effort to assure that staff is available to communicate with an individual using their primary means of communication. In the case of unplanned respite, it may not be a realistic expectation for the agency to have someone available immediately upon entry of the individual who will be able to communicate with an individual through his or her primary language. Nevertheless, the provider needs to make every effort to seek out appropriate supports to be able to use the individual's primary means of communication.

C. Supporters assist people to communicate with and be understood by others.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

Outcome 2: People make choices in their everyday lives

Indicators:

A. People make choices about their routines and schedules.
Application: Applies to both planned and unplanned respite.
Guidelines: The degree to which people have control over their everyday choices will vary depending on the type of respite service:

- In a planned respite situation, staff should make every effort to honor a person's choices, and an array of choices should be available. During intake, the provider should learn about individuals' preferences and routines so that, in as much as possible, staff can incorporate them into the daily activities at respite.
- In some unplanned respite situations, where the initial goal is to stabilize the individual, there may initially be more structure and less choices available. Once the individual is stabilized his or her preferences should be considered in the same way as in planned respite.

B. People make choices about the work and household tasks for which they are responsible.
Application: Does not apply to planned or unplanned respite.
Guidelines: In a respite situation, where many people are constantly coming and going, there may be very few choices concerning household tasks. Household routines and jobs may not be the responsibility of individuals as they're not there for any length of time and it is not their home.

C. People spend their leisure time in personally satisfying ways.
Application: Applies to both planned and unplanned respite.
Guidelines: Individuals do leisure activities that are satisfying within the array of options that the provider has available. As a part of intake the provider should learn about individuals' preferences for leisure activities so that these can be incorporated into the respite stay.

Outcome 3: People are the primary decision makers in their lives

Indicators:

A. People develop their personal goals.
Application: Does not apply to planned or unplanned respite**.**

B. People influence who provides their supports.
Application: Does not apply to planned or unplanned respite.

C. People control important decisions about their home and home life.
Application: Does not apply to planned or unplanned respite.

Quality of Life Area: Community and Social Connections

Outcome 1: People are integrated into their community

Indicators:

A. People live and work in communities with resources they want and need.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

B. People use the same community resources as others on a frequent and ongoing basis.
Application: Applies to both planned and unplanned respite.
Guidelines: Individuals are supported to participate in individualized activities and, as far as possible, the provider is able to meet individuals' preferences during their respite stay.

Outcome 2: People are connected with their community

Indicators:

A. People are supported to explore their personal interests and options for community involvement.
Application: Does not apply to planned or unplanned respite.

B. People are involved in activities that connect them to other people in the community.
Application: Does not apply to planned or unplanned respite.

Outcome 3: People have relationships

Indicators:

A. People are supported to maintain and enhance relationships with family, friends and co-workers.
Application: Applies to both planned and unplanned respite.
Guidelines: Due to the nature of a respite service, individuals utilizing it are likely to be away from most of their familiar friends and family. To the extent possible and appropriate, however, the respite provider should assist individuals to maintain their relationships.

B. People are supported to develop new friendships.
Application: Applies to both planned and unplanned respite.

Guidelines: The respite provider supports individuals to socialize with others they come in contact with during their respite stay.

C. People are supported to explore, define and express their need for intimacy.
Application: Applies to both planned and unplanned respite.
Guidelines: In this situation, the provider does not have a responsibility for long range training and support to assist an individual to define his/her needs in the area of intimacy. However, the provider should offer support and training to their staff so that they can respond appropriately to issues which might emerge during the course of an individual's stay at the respite home.

Quality of Life Area: Personal Growth and Accomplishment

Outcome 1: People accomplish their goals

Indicators:

A. People's goals are the basis for actions and supports.
Application: Applies to both planed and unplanned respite.
Guidelines: The focus at respite is to support the " intended purpose" of each person's stay (e.g., social/recreational, behavioral stabilization). The provider has the needed supports, services and resources (e.g., clinical) to meet the purpose of the stay.

B. There is a match between what people are doing now and what they want to do in the future.
Application: Does not apply to planned or unplanned respite.

C. People have access to needed resources in order to accomplish their goals.
Application: Applies to planned and unplanned respite.
Guidelines: The focus at respite is to support the " intended purpose" of each person's stay (e.g., social/recreational, behavioral stabilization). The provider has the needed supports, services and resources (e.g., clinical) to meet the purpose of the stay.

Outcome 2: People have autonomy

Indicators:

A. People complete day-to-day activities, tasks and chores as independently as possible.
Application: Applies to both planned and unplanned respite.
Guidelines: Supports are available for individuals to use their current skills and be as independent as possible. For example, if an individual uses a plate guard at home, he should be support to bring it with him and to use it during his respite stay.

B. People have access within their home and workplace.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

Outcome 3: People grow through their life experiences

Indicators:

A. Supporters are sensitive and attuned to both small and large events in people's lives.
Application: Applies to both planned and unplanned respite.

B. People are encouraged to understand experiences in their lives.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

C. People are supported to grow from events in their lives that affect them.
Application: Applies to both planned and unplanned respite.
Guidelines: None needed.

Guidelines: In some instances pertinent information about the individual's life situation may not be known upon entering respite. Shortly after the person enters respite, the provider gathers needed information in order to support with any emotional issues that might be of concern to the individual.